

# Retaining Hispanics: Lessons from the Hispanic Community Health Study/Study of Latinos



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# Objectives

Understand factors associated with motivations to participate in a longitudinal cohort study

Identify strategies to increase satisfaction with participation in a longitudinal cohort study

Discuss strategies for retaining a large sample of Hispanic/Latino participants in a longitudinal cohort study



# Importance of Inclusion

- 18% of the U.S. population identifies as Hispanic/Latino
- Hispanic/Latinos population is fastest growing population in the U.S.
- Inclusion promotes scientific validity and generalizability
- Inclusion underscores the role of social contexts in health and disease sequelae
- Inclusion allows for evaluation of effect modification

# Challenges of Inclusion



## Participant Perspective

- Mistrust of researchers
- Logistical barriers
- Competing demands
- Privacy and confidentiality
- Stigmatization

## Researcher Perspective

- Lack of social ties to communities
- Limited knowledge of language and culture
- Limited experience with sampling design strategies
- Concerns about power and variation

# HCHS/SOL Prospective Cohort Design



- 16,415 non-institutionalized, self-identified Hispanic/Latinos age 18-75 in 2008-2011
- Four Urban Sites: Bronx, NY; Chicago, IL; Miami, FL; San Diego, CA
- Two-stage stratified, random cluster sample
- Three Clinic Visits: Visit 1 (2008-2011); Visit 2 (2014-2017); Visit 3 (2020-2023)
- Annual Follow-Up Phone Interviews

**80% Retention Rate**

# Retention Starts with Sample Design



- **Population-based** utilizes a known sampling frame and results in generalizable data
- **Clustering** lowers the cost of data collection and builds samples from communities with social connections; increases std. errors
- **Stratification** ensures representation across different types of community members; lowers std. errors

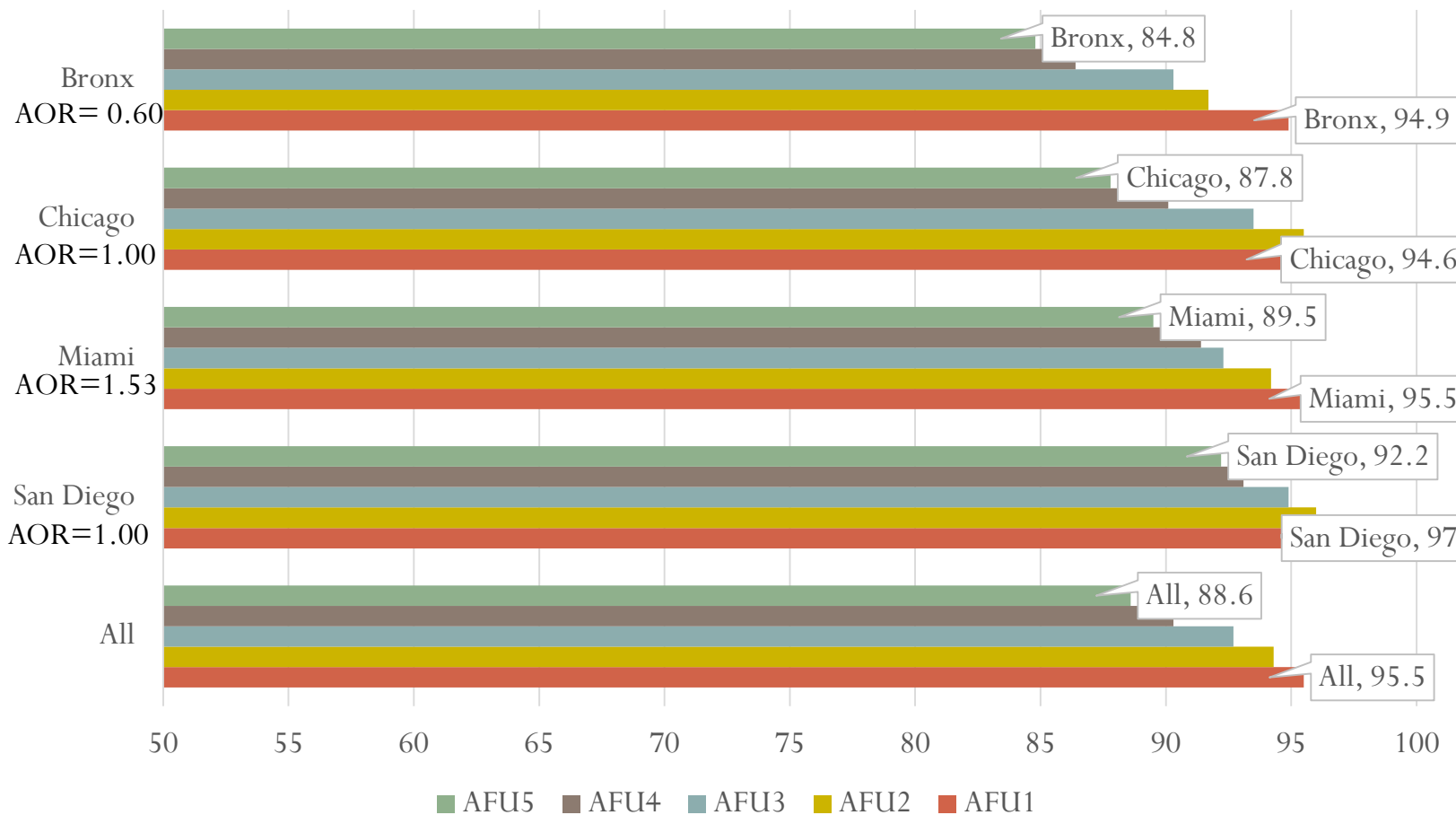
# Retention builds upon recruitment



- **Community Based** – Investing in building long, lasting partnerships (e.g., feel-physical presence, see-identifiable logo, hear-PSAs)
- **Informed Consent** – Investing in educating participants and building rapport (e.g. read it, hear it, see it)
- **Strong Motivations** – Values, Duty, and Loyalty



# HCHS/SOL Response Rate Data by Site and AFU



# Retention Strategies: Community and Personnel



- **Community Engagement:** Learn from the community, develop support for the study, and share results
- **Study Personnel:** Promote professionalism, team work, training, and continuity
- **Recruitment:** Build rapport and trust during initial contacts

# Recruitment Strategies: Incentives, Costs, and Benefits



- **Financial Incentives:** Provide a meaningful incentive commensurate with the time required for participation.
- **Non-Financial Incentives:** Show appreciation for participants engagement with the study and appeal to sense of altruism and norms of cooperation.
- **Costs:** Minimize costs of participation in the study through reimbursement, site location, flexible hours and participation options, efficient use of participant time
- **Benefits:** Provide tangible benefits to recipients (e.g., health test results, referrals, social support)

# Recruitment Strategies: Communications and Tracking



- **Communication:** Maintain regular contact with participants and keep them informed about the study.
- **Tracking:** Keep information on participants current by keeping multiple contacts, regularly updating contact information, subscribing to location services, street-level outreach

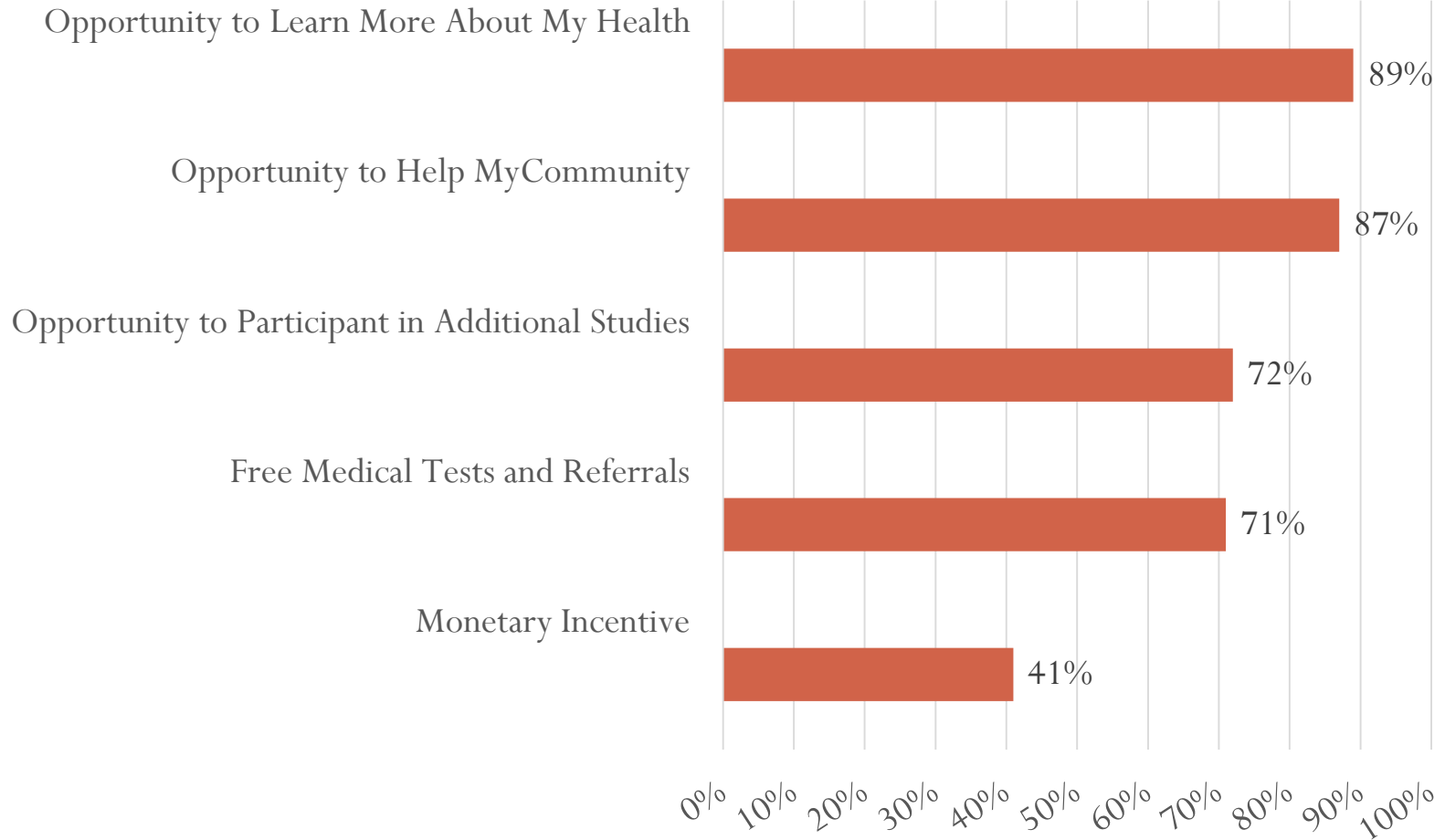
# Characteristics of Participants, Visit 2 Feedback Interview (N=5,227)



- **Demographic Background:** Female (54%), Age (~43), Mexican (37%), Cuban (22%), Puerto Rican (15%), US-Born (29%)
- **Socio-Economic Background:** <HS Grad(32%), Not Employed (50%), <\$25K (52%), Married/ Cohabiting (49%), No Children (25%)
- **Health Characteristics:** Good-Excellent SRH (72%), SF-13 MHS (49), SF-12 PHS (49)
- **Interview Characteristics:** Spanish (77%), >1 Venipuncture (10%), ancillary study participant (35%)

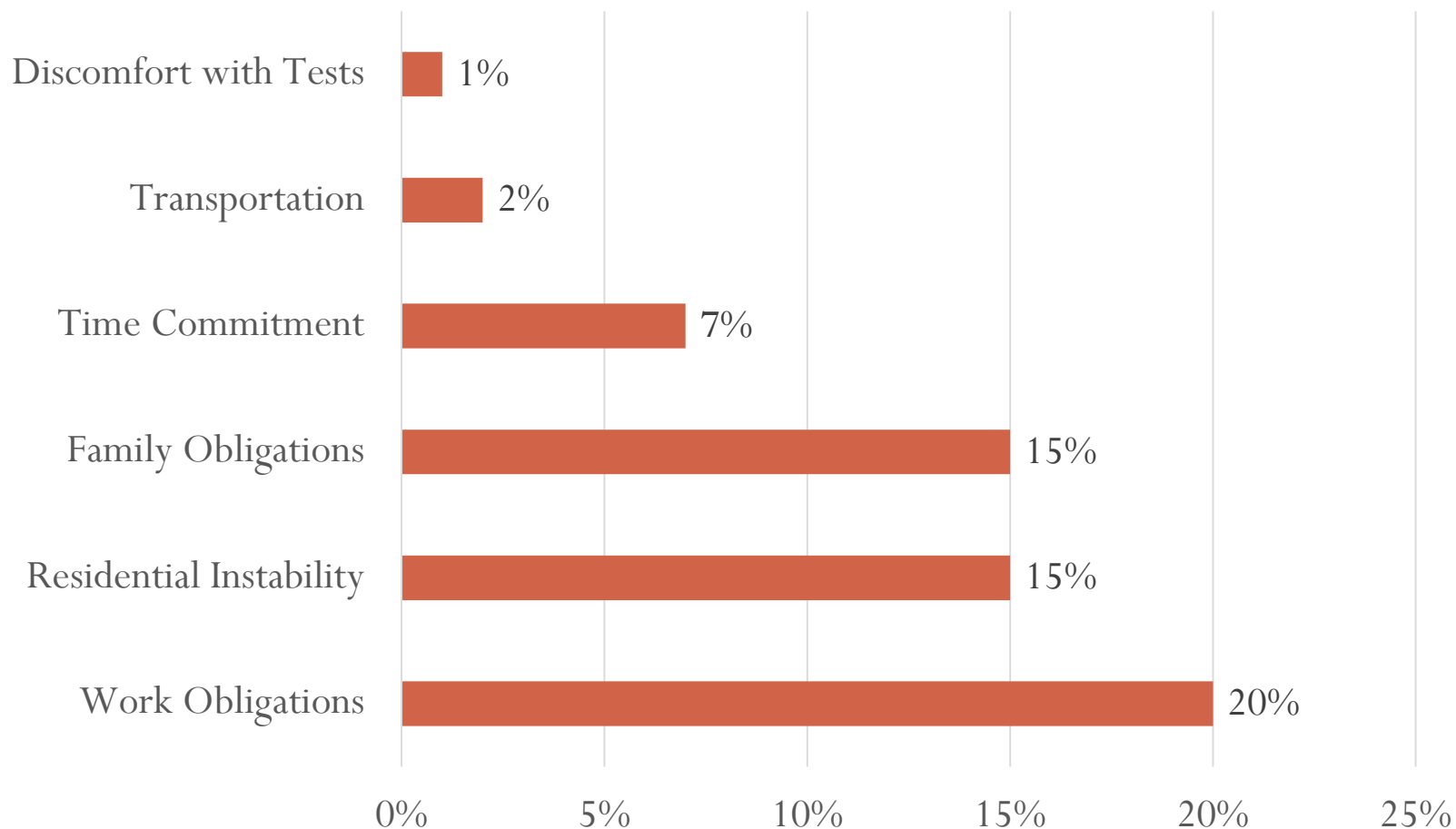
# Participant Motivations

(N=5227 at Visit 2)

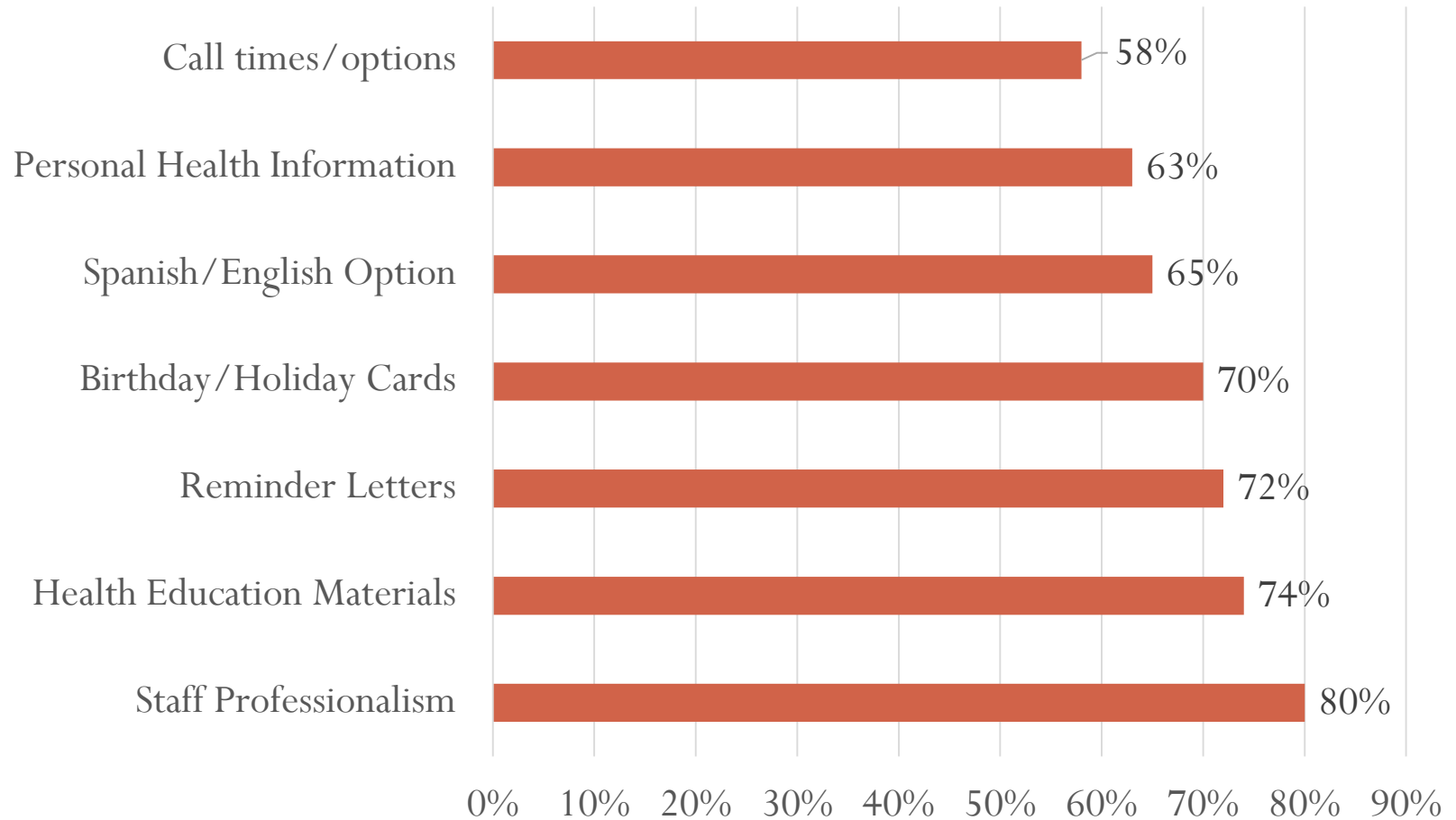


# Challenges for Participation

(N=5227 at Visit 2)



# Participant Satisfaction with Retention Activities (N=5227 at Visit 2)





# Characteristics of Participants at Visit 1 (N= 16,243)



- **Demographic Background:** Female (52%), Age (~41), Mexican (37%), Cuban (19%), Puerto Rican (16%), US-Born (31%)
- **Socio-Economic Background:** <HS Grad(32%), Not Employed (49%), <\$25K (51%), Married/ Cohabiting (49%), No Children (26%)
- **Health Characteristics:** Good-Excellent SRH (74%), SF-13 MHS (49), SF-12 PHS (50)
- **Interview Characteristics:** Spanish (75%), >1 Venipuncture (9%), ancillary study participant (39%)

# Demographic Characteristics of Persistent Participants (AFUs1-5, N=15,930)



Demographic Characteristic	OR	95% CI
Female (vs. Male)	1.47	1.34, 1.62
Age yrs	1.03	1.03, 1.04
Hispanic/Latino Heritage (vs. Mexican)		
Dominican	1.01	0.78, 1.30
Central American	0.90	0.70, 1.17
Cuban	0.80	0.60, 1.07
Puerto Rican	0.96	0.74, 1.25
South American	0.93	0.71, 1.20
Other	0.94	0.69, 1.30
Nativity and Years in U.S. (vs. US Born)		
FB < 10 yrs in US	1.40	1.12, 1.75
FB 10-20 yrs in US	1.32	1.07, 1.63
FB > 10 yrs in US	1.25	1.01, 1.54

# SES Characteristics of Persistent Participants (AFUs1-5, N=15,930)



SES Characteristic	OR	95% CI
HS Graduate/GED or Greater (vs. < HS)	1.24	1.11, 1.39
Employment (vs. Not Employed)		
Employed ≤ 35 hrs/wk	0.98	0.85, 1.14
Employed 35-45 hrs/wk	1.16	1.00, 1.34
Employed > 45 hrs/wk	0.97	0.81, 1.17
Income ≥ \$25K/yr (vs. < \$25K/yr)	1.29	1.14, 1.45
Married/Cohabiting (vs. Single)	1.17	1.05, 1.32
No Children (vs. Any Children)	1.21	1.03, 1.42

# Health and Interview Characteristics of Persistent Participants (AFU1-5, N=15,930)



Health Characteristics	OR	95% CI
Mental Health Functioning	1.10	1.04, 1.17
Physical Health Functioning	0.99	0.94, 1.05
Interview Characteristics		
Interview in Spanish (vs. English)	1.01	0.86, 1.18
Venipuncture Attempt (vs. 1 Attempt)		
No Attempt	0.22	0.11, 0.44
> 1 Attempt	0.92	0.77, 1.10
Participated in 1+ ancillary study (vs. 0)	2.60	2.30, 2.94
Location (vs. San Diego)		
Bronx	0.60	0.46, 0.79
Chicago	1.00	0.82, 1.22
Miami	1.53	1.12, 2.10

# Influence of Residential Mobility and Call Frequency on Persistence



- Avg. Call Attempts: 5.7
  - Compared to San Diego, significantly lower in Miami, (-.47), Chicago (-.37), and Bronx (-.13)
  - More attempts is associated with lower persistence; harder to reach participants require more calls
- % Reported Zip Code Change: 42%
  - Compared to San Diego, odds of a change being reported were higher in Miami (OR=1.89) and not significantly different in Bronx or Chicago
  - Compared to no change in a zip code, an updated Zip Code and no updated zip code are associated with lower persistence



# Lessons Learned

- High retention rates for Hispanics/Latinos in large prospective cohort studies are possible. In each of the first five-years of annual follow-up, the HCHS/SOL maintained response rates of 88.6% to 95.5%.
- To achieve high retention rates, studies of Hispanics/Latinos should employ bilingual/bicultural staff who treat participants with respect and professionalism, use culturally-tailored retention materials to maintain regular contact with participants, and provide flexible interview schedules to allow participants to coordinate study participation with their family and work obligations.
- The most difficult Hispanic/Latino populations to retain include young, single, US-born males without a high school diploma or GED, incomes under 25K, and weak labor market ties. These participants also tend to be more mobile.
- Additional efforts, including more frequent calls, more updates of contact information, and greater financial incentives, may be needed to retain these harder-to-reach populations.



# Thank you!

For more information, please see published article in American Journal of Epidemiology (DOI: [10.1093/aje/kwaa003](https://doi.org/10.1093/aje/kwaa003)) or Contact [Perreira@email.unc.edu](mailto:Perreira@email.unc.edu)